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Dr. Marcella Nunez-Smith
COVID-19 Health Equity Task Force
Office of Minority Health
Department of Health and Human Services

October 28, 2021

RE: COVID-19 Health Equity Task Force's Final Meeting

Dear Dr. Nunez-Smith:

Thank you for the opportunity to submit comments today regarding Post-Acute Sequelae of SARS-CoV-2 infection, also known as “PASC” or “Long COVID.”

We are grateful to the COVID-19 Health Equity Task Force (HETF) for your dedicated work and thoughtful recommendations advanced over the past nine months. We are also grateful for the COVID HETF’s willingness to meet with AAPM&R and hear about the crisis of Long COVID that has been happening in tandem with the COVID-19 public health emergency (PHE).

AAPM&R provided thorough comments on the HETF’s interim recommendations during the September 30th meeting and would like to take this opportunity to reiterate our support for several HETF recommendations as the HETF makes its final report. In particular, we thoroughly support the critical discussion of Long COVID and related recommendations made by the Task Force regarding mandating data collection, research, and transparency; increasing awareness and access to services; and engaging

communities. These recommendations are squarely in line with AAPM&R’s National Call to Action on Long COVID, imploring the Biden Administration to develop and implement a comprehensive crisis plan that addresses resources to build necessary infrastructure, equitable access to care for all patients, and continued funding for research that advances medical understanding of PASC¹. **AAPM&R urges the HETF to include these recommendations in its final report to President Biden, and we offer our additional suggestions below.**

Need for a Federal Body to Coordinate the Long COVID Response

The interim recommendations are comprehensive and wide-ranging, as is necessary to address such a major crisis. The scope of the Long COVID crisis is massive and requires a proportionate federal response. It is currently estimated that 10-30%² of people who had COVID-19, including asymptomatic cases, will experience prolonged effects related to their previous COVID-19 infection. Even considering the conservative estimate of 10%, this represents over 12 million people³ given the infection rate of this virus. This already overwhelming number is likely to substantially increase

¹ For more information on AAPM&R’s National Call to Action, please see AAPM&R’s website: <https://www.aapmr.org/members-publications/covid-19/call-to-action>.

² Rubin R. As Their Numbers Grow, COVID-19 “Long Haulers” Stump Experts. JAMA. 2020;324(14):1381–1383. doi:10.1001/jama.2020.17709.

³ Estimated Disease Burden of COVID-19. Centers for Disease Control and Prevention. Updated May 29, 2021. <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html>

due to the dramatic resurgence of COVID-19 due to the Delta variant.

AAPM&R has created a [dashboard](#)⁴ to visualize the ongoing number of people expected to experience long COVID-19 symptoms. This dashboard can provide a snapshot of estimated populations nationally, by state, and by county. The estimates in the dashboard demonstrate the need for policy solutions is only going to grow over the coming months. The Task Force's recommendation for an interagency-led campaign focusing on Long COVID patients' rights and support is directly aligned with AAPM&R's push for a federal commission or otherwise coordinated diverse federal response.⁵

However, we believe this interagency approach should be more expansive to ensure the Task Force's proposed federal interagency-led campaign effectively and efficiently addresses the myriad of needs in the Long COVID crisis, including but not limited to rights and support. **AAPM&R urges the HETF to recommend the federal interagency campaign direct a whole-of-government response far more comprehensive than a communications campaign. We recommend the federal interagency entity be led by the White House or at senior levels within the Department of Health and Human Services and be tasked with**

⁴ AAPM&R PASC Dashboard. <https://pascdashboard.aapmr.org/>.

⁵ AAPM&R Call to Action: America Needs a Federal Commission to Develop a Comprehensive National Plan to Defeat the Long COVID "PASC" Crisis. https://www.aapmr.org/docs/default-source/advocacy/pasc-commission-sign-on-with-signatures.pdf?sfvrsn=7e9b227c_70.

development of a crisis plan (building off the HETF’s recommendations) to address the immediate and long-term impacts of Long COVID-19, both at the individual and national levels.

The actions taken by the Administration in July 2021 to acknowledge Long COVID as a potentially qualifying condition for disability protections under various federal civil rights laws is a crucial first step. We appreciate the HETF’s recommendations regarding myriad policies to enhance supports for minoritized, marginalized, and medically underserved communities to help address the financial, health, physical, and social impacts of Long COVID, many of which are compounding pre-existing disparities and inequities. AAPM&R believes that equitable access to strengthened safety-net care, including disability evaluations and benefits, will be a pivotal factor in an effective response to this crisis.

Convening and empowering a high-level federal entity, with the requisite authorities and recognition from federal agencies and other stakeholders, is necessary to develop and implement the large-scale response that is needed to meet the Long COVID crisis at hand.

Long COVID Federal Advisory Committee

AAPM&R applauds the HETF’s recommendation to form a Federal Advisory Committee on Long COVID. It is absolutely critical, as noted in the interim recommendations, to magnify the patient voice and include

disability advocates from the broader community who can speak to the hurdles individuals with Long COVID may face when dealing with new long-term or permanent debility. We urge the Task Force to recommend inclusion of provider representatives in this Committee as well. Physiatrists have been recognized as one of the leading specialties for assessing and treating patients experiencing Long COVID. Given the Academy's experience and physiatrists' medical expertise in working with patients with Long COVID and other post-viral, complex, and debilitating illnesses, as well as our membership's experience opening and running multi-disciplinary post-COVID clinics, **the AAPM&R is an invaluable resource and should be included in such an Advisory Committee.**

Physiatrists, as trained physician experts in medical rehabilitation, have played and continue playing a unique role in helping American patients recover from the acute phase of COVID-19, working on the front lines of the pandemic since the beginning of the public health emergency. Our members have transformed inpatient rehabilitation facilities to take care of acutely ill patients to help decompress the massive surge of patients being admitted to acute care hospitals. Our members treat recovering COVID-19 patients who had been in the intensive care unit and suffered multi-system organ failure and complications (such as strokes and critical illness polyneuropathy). These patients require rehabilitation to regain their previous functional

abilities and independence. While members continue to treat these patients, over the past year or more our members' outpatient practices began treating patients suffering from the prolonged effects of Long COVID. A Federal Advisory Committee with an appropriate diversity of expertise is essential to ensuring the federal response is well-informed and addresses the needs of all individuals dealing with the impact of Long COVID.

Support for Multi-Disciplinary Clinics

The HETF's interim recommendations also recognize the important contributions and future potential of multi-disciplinary Long COVID clinics, which have been a key part of the treatment paradigm for individuals with Long COVID. There are clinics serving patients nationwide, which provide a central hub to diagnose, evaluate, and coordinate care for individuals dealing with the multi-faceted, complex, and often confusing symptoms of this condition. The AAPM&R has convened a Multi-Disciplinary PASC Collaborative⁶ of 32 of these clinics that meet regularly to share key findings, best practices, and develop clinical guidance statements to ensure practical knowledge is disseminated throughout the medical field as quickly as possible. This Collaborative is well-positioned to help implement the recommendation for a "Long COVID health equity learning community

⁶ For more information on the PASC Collaborative, please visit: <https://www.aapmr.org/members-publications/covid-19/multidisciplinary-quality-improvement-initiative>

infrastructure,” an integral part of an effective Long COVID response.

AAPM&R and its members have long recognized the critical need to ensure that clinical expertise is made widely available in all settings, especially for rural and other underserved areas.

Individuals experiencing Long COVID are subject to the same systemic barriers to care that individuals with other complex, chronic conditions experience. For instance, when a patient visits their primary care provider to discuss their Long COVID symptoms, they are often provided with several referrals to specialists to address the confluence of their symptoms. Such patients may receive a referral to a cardiologist, pulmonologist, neurologist, psychiatrist, and orders for various labs and other tests. This puts the patient in the position of coordinating their own complex care and dealing with numerous hurdles, including securing timely appointments, traveling to and from multiple providers, and managing treatment plans, not to mention meeting the financial needs associated with this care. This can be particularly difficult for patients with Long COVID who are suffering new physical and cognitive impairments. The multi-disciplinary clinic approach, however, creates a hub where a patient can see a physiatrist, consult with other specialists, complete their testing, and meet with needed therapists through a comprehensive, coordinated approach.

In Collaborative discussions, the most commonly reported barrier for these clinics were lack of resources in treating these patients, including lack of clinicians and financial coverage for patients to receive the care that they need. Given this lack of resources, patients often must wait several months to access these clinics. Furthermore, even when seen, patients may have difficulty receiving the assessments and treatments they need. Countless patients are denied testing (echocardiograms, pulmonary function tests) and treatments (neuropsychology, speech therapy, and medications). **For these reasons, AAPM&R supports providing funding to these multi-disciplinary clinics, including to disseminate medical equipment to patients, expanding access to preventive treatment for Long COVID.**

We thank the Task Force for its leadership in recognizing this critical issue for many across the country and appreciate the opportunity to submit this written testimony. **We offer our support and experience as an organization and on behalf of the psychiatry profession to the federal government through the Long COVID crisis. AAPM&R and the Multi-Disciplinary PASC Collaborative are a resource and we urge the federal government to include the voice of psychiatry in any federal advisory committee or other stakeholder group working on these critical policy**



issues. Thank you again, Dr. Nunez-Smith and the entire HETF for your thoughtful, dedicated, hard work during this time.

Please reach out to me with any questions or concerns at rsingh@aapmr.org or 847.737.6030.

Sincerely,

Reva Singh, J.D., M.A.
Director of Advocacy and Government Affairs